

Measurement of psychological distress in palliative care

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Research investigating the psychological distress of palliative care patients has contributed to our understanding of the needs and experiences of individuals approaching death. This paper aims to provide a brief review of such measurement of psychological distress in palliative care, focusing on established psychiatric and psychological research tools, and quantitative research methods. This includes clinical screening and diagnostic assessment instruments used to identify key distress-related symptoms and the presence of common clinical syndromes, such as depression, anxiety, delirium, as well as the broader psychological dimensions of suffering, such as existential concerns, spirituality, hope and demoralisation. There are important considerations in undertaking psychological research in palliative care, such as maintaining a balance between the methods and measurements that will address key research questions, and sensitivity to the range of physical and emotional demands facing individuals at the point of receiving palliative care. The clinical application of psychological and psychiatric research tools and methods can aid the detection of psychological distress, aid the thorough assessment of the psychological dimension of the patients' illness and care, aid the identification of individuals who would benefit from specific psychotherapeutic or pharmacologic interventions, and the evaluation of response to treatments. *Palliative Medicine* 2006; **20**: 779–789

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Introduction

Providing optimal symptom relief and alleviating patient suffering requires that palliative care clinicians attend to the issue of psychological distress. Psychological distress has been conceptually defined as a 'unique, discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary, or permanent, to the person'.¹ The nature of the experience may be psychological (cognitive, behavior, emotion), social and/or spiritual, such that an individual's ability to cope with the illness, its physical symptoms and treatment are effected.² This paper will provide a brief overview of research, addressing psychological distress in palliative care and focusing on research instruments and methods. This will include specific attention to common clinical symptoms and syndromes, along with general distress-related themes. Research tools to assess psychological distress include generic screening instruments, specific psychological screening tools, and diagnostic instruments based on structured clinical interviews. While qualitative research methods in palliative care are of utmost importance, this

review will focus exclusively on quantitative approaches to measuring distress among patients nearing death. The clinical application of such research tools and methods can aid the detection of psychological distress, the identification of individuals who would benefit from specific psychotherapeutic or pharmacologic interventions, and the monitoring of response to treatments. Nevertheless, while clinical rating scales may assist in the evaluation of psychological symptoms and treatment needs, they do not replace the important role of skilled communication and comprehensive clinical evaluation in palliative care.

The scope of psychological distress in palliative care

Psychological distress in patients with serious medical illnesses is best understood as existing along a continuum; while many individuals will experience responses, such as fear, sadness and grief at varying times in response to their disease, others may progress to develop more clinically significant conditions.^{3,4} Psychological morbidity, such as depression, anxiety, and adjustment disorders, are common in cancer patients, with between 35 and 50% of patients experiencing these psychological problems.^{5,6,7} In recognition that non-cancer patients require palliative care services,⁸ consideration of the

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psychological distress experienced by patients with medical illnesses other than cancer is warranted. Within non-cancer populations, depression has been identified in 19–23% of stroke survivors,⁹ 50% of those with Parkinson's disease,¹⁰ and 20–30% amongst those with dementia disorders.¹¹

Despite its ubiquitous nature, the literature consistently indicates that psychological distress in palliative patients tends to be under-diagnosed and under-treated.^{12,13,6,14} Given its effect on patient well-being, social functioning, perceptions of symptom distress and length of hospital stay, the importance of proper recognition and treatment of psychological distress cannot be overstated.⁴

While measuring distress within a conventional psychiatric paradigm is of critical importance, patients nearing death often experience distress that is not well characterised within the context of DSM-IV phenomenology.¹⁵ Even mild to moderate distress can play an important role in shaping the emotional experience of patients in the last weeks of life.¹⁶ Distress, often described in terms of suffering, hopelessness, and existential or spiritual crisis, can undermine the capacity for pleasure, take away a sense of meaning, diminish the ability to connect with others, and overall, have a negative effect on quality of life.¹⁷ For instance,¹⁸ reported that sources of distress within a cohort of 162 terminally-ill Japanese hospice inpatients included feeling a sense of dependency (39%), meaninglessness in present life (37%), hopelessness (37%), feeling a burden to others (34%), loss of social role functioning (29%), and feeling emotionally irrelevant (28%). Similarly,¹⁹ reported that 51% of cancer outpatients struggled with issues related to overcoming fears, finding hope (42%), and meaning in life (40%). Clearly, finding ways of tracking and

measuring end-of-life distress of this nature is of vital importance.

Just as the single screening item approach has been popularised in the depression literature,²⁰ the National Comprehensive Cancer Network (NCCN) has developed a single-item measure to broach end-of-life distress. This approach is conceptually flexible and inclusive, in order to identify and measure various sources of distress within this patient population.²¹ They chose the term distress to describe psychological, social and spiritual domains of concern, primarily because it does not carry any stigmatising connotations that can accompany psychiatric diagnoses, while at the same time, can be inclusive in its meaning. This continuum of distress can extend from feelings of vulnerability, sadness and fear, to depression, generalised anxiety, panic, feeling isolated or spiritual crisis. This approach – by way of having patients rate themselves on a distress thermometer – provides an easy way of measuring and tracking distress along a continuum of severity (Figure 1).²¹ The NCCN has also developed guidelines to address each facet of distress, as it arises in palliative care patients (<http://www.nccn.org>). To date, the specificity and sensitivity of the single-item distress thermometer has been demonstrated in a number of studies.²²

Similarly,²³ developed a single-item approach to identify spiritual distress at the end-of-life. This item, consisting of a 5-point Likert scale, asks patients to rate the extent to which they 'were at peace', and according to its authors, provides a 'non-threatening gateway' to elicit patient and family concerns within this domain. They reported no variation in responses due to demographic factors, and found that feeling at peace was strongly correlated with emotional and spiritual well-being. With an equal correlation with the faith and

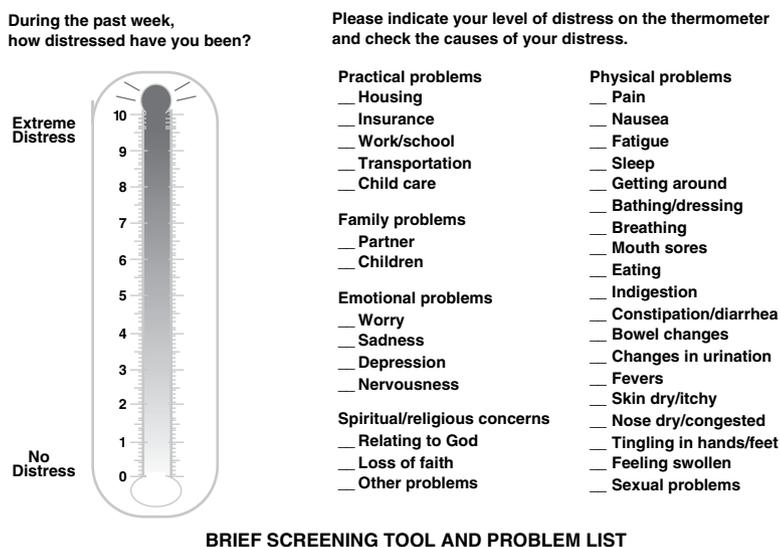


Figure 1 Distress thermometer

purpose subscales of the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp),²⁴ they conclude that this approach can be applied to traditional and non-traditional (or secular) definitions of spirituality.

Other investigators have taken a multi-dimensional approach to measuring distress. Just as the Edmonton Symptom Assessment Scale (ESAS) tracks symptom distress across a variety of domains,^{25,26} have developed the Structured Interview Assessment of Symptoms and Concerns in Palliative Care (SISC) to measure various sources of distress or concerns that arise in the context of end-of-life care. This novel psychometric provides a reliable and valid approach to the assessment of key symptoms and concerns at the end of life. Besides tapping into physical aspects of the palliative experience (pain, drowsiness, nausea, weakness, dyspnea), this instrument also broaches several areas of psychological and existential distress, including loss of control, loss of dignity, sense of burden, anxiety, depression, loss of interest, hopelessness and desire for death. Using a brief interview approach, each item is rated by clinicians, indicating the severity of the problem on a 7-point scale (none to extreme). The SISC has been shown to have excellent inter-rater reliability (intraclass correlations >0.90) and at least moderate temporal stability (test-retest correlations ranging from 0.50 to 0.90). Its concurrent validity was established on the basis of concordance between interview items and VAS measures ($r > 0.70$).

Several multi-itemed, thematically coherent measures of distress – or proxies thereof – are emerging in the literature.²⁷ For example, developed a specific scale to measure suffering in patients with end-stage dementia, coined the Mini-Suffering State Examination (MSSE). As this information is not directly accessible, it must be inferred from patients in other ways. The MSSE consists of 10 questions (yes/no format) based on clinical experience, including (1) not calm, (2) screams, (3) pain, (4) decubitus ulcers, (5) malnutrition, (6) eating disorders, (7) invasive action, (8) unstable medical condition, (9) suffering according to medical opinion, (10) suffering according to family opinion. They report good inter-rater reliability ($\kappa = 0.791$), and concurrent validity ($r = -0.796$) with the ‘comfort assessment in dying with dementia scale’ (CAD-EOLD).²⁸

Used the total mood disturbance (TMD) scores of the Profile of Mood States to examine predictors of psychological distress in ambulatory lung cancer patients. Interestingly, they found the disease-related variables, such as disease stage and performance status, were not predictive of psychological distress. On the other hand, being female, living alone, having less support from children and a helplessness/hopelessness coping style

were predictive of psychological distress in this patient population.

The FACIT-Sp is a 12-item, self-report measure, designed to assess the nature and extent of spiritually-based distress, or alternatively, well-being.²⁴ The FACIT-Sp is comprised of two subscales: one measuring a sense of meaning and peace, and the other assessing the role of faith. It has been shown to have good internal consistency, convergent validity, reliability and a significant relation with quality of life. Of interest, a study of 162 patients dying of cancer or Acquired Immunodeficiency Syndrome (AIDS) demonstrated a statistically significant negative association between the Hamilton Depression Rating Scale (HDRS) scores and FACIT total scores ($\beta = -0.30$, $P < 0.001$).²⁹ This indicates that individuals scoring higher on the spiritual measure were less depressed. In a sample of 160 hospitalised cancer patients admitted for terminal care,³⁰ assessed the relationship between spiritual well-being, depression, and end-of-life despair. The study demonstrated significant negative correlations between spiritual well-being and desire for hastened death ($r = -0.51$, $P < 0.0001$), hopelessness ($r = -0.68$, $P < 0.0001$), and suicidal ideation ($r = -0.41$, $P < 0.0001$). Thus, it appears that spiritual well-being offered some protection against end-of-life despair, based on the additional findings that depression was significantly correlated with a desire for hastened death in patients low in spiritual well-being ($r = 0.40$, $P < 0.0001$), but not in those high in spiritual well-being.

Distress, expressed by way of coveting an earlier death, has been measured using a single-item approach, as well as with a multi-itemed, thematically coherent psychometric. Chochinov *et al.* measured will to live (WTL) and desire for death, using a WTL visual analogue scale and a single desire for death interview item, respectively.^{31–33} developed a 20-item Schedule of Attitudes toward Hastened Death (SAHD). The total SAHD score correlated significantly with the clinician rating on the Desire for Death Rating Scale and with ratings of depression and psychological distress. These results indicate that the SAHD is a reliable, valid measure of desire for death among patients with HIV/AIDS or cancer.³⁴

While a complete overview of quality of life measures is beyond the scope of this review, there are numerous instruments including, for example, the FACIT Quality of Life measure,³⁵ the Missoula-VITAS Quality of Life Index,³⁶ the McGill Quality of Life tool,³⁷ the QUALE,³⁸ the EORTC questionnaires/(QLQ-C15-PAL),³⁹ the Functional Assessment of Cancer Therapy (FACT) modules,⁴⁰ and the Quality of Life Scale (QLS).⁴¹ The latter comprises of two VAS measures, asking patients to rate their current quality of life, and their satisfaction with their quality of life, respectively. Other measures are much more detailed and multi-dimensional, in spite of their various components being subsumed under the

rubric of quality of life. As in all instances of designing a palliative care research protocol, the choice of measures should be based on what is most likely to answer the research question(s), while at the same time, minimising unnecessary protocol burden.

Specific psychological symptoms and psychiatric disorders

Depression

Psychological distress may manifest in the form of depression. Variable rates of depression in palliative patients have been reported, ranging from 3.7 to 58%,⁴² with best estimates placing the point prevalence of operationally defined major depression in palliative patients at 15%,⁴³ more than double the maximum 12-month prevalence rates for major depressive disorder found in general population studies (3.9–6.7%).^{44,45} The variability in rates of depressive disorders among different studies of cancer patients has been attributed to the heterogeneity in defining depression across prevalence studies, and the populations examined.^{43,6}

There are numerous methods to assess depression, including diagnostic classification systems, structured diagnostic interviews, and self-report measures¹⁴ (Table 1). Structured diagnostic interviews, such as the Diagnostic Interview Schedule (DIS),⁴⁶ the Composite International Diagnostic Interview (CIDI),⁴⁷ the Schedule for Affective Disorders and Schizophrenia (SADS),⁴⁸ and the Structured Clinical Interview for the DSM-III-R (SCID),⁴⁹ have sound psychometric properties. However, they can be quite burdensome to patients when administered in their entirety, thus limiting their utility in palliative populations;⁶ their reliability and

validity in these populations requires further assessment. The latter is partly due to the problems in applying existing diagnostic criteria for major depression among patients with severe physical illness, and the risk of a high rate of false positives due to the number of physical symptoms that may mimic symptoms of depression (eg, fatigue, appetite and weight change). Specific modifications of diagnostic criteria for depression in medically ill patients have been recommended for clinical and research purposes.^{50,51}

Depression: diagnostic measures and screening tools. In addition to establishing validity and reliability, researchers interested in measuring depression in those with advanced illness require instruments that are minimally burdensome, acceptable to patients, and easy to administer and score.^{3,52} The utility of brief screening measures for depression has been identified in the literature.⁵³ In a study of palliative cancer patients,²⁰ compared the performance of four brief screen measures for depression: (i) a single-item interview assessing depressed mood; (ii) a two-item interview assessing depressed mood and loss of interest or pleasure in activities; (iii) a visual analog scale; and (iv) the Beck Depression Inventory Short Form. Using a semi-structured diagnostic interview for depression as the gold standard against which the screening performance of the brief measures were evaluated, these researchers found that the single-item interview – applied using a threshold stringency equivalent to patients feeling depressed ‘most of the time’ – outperformed the questionnaire and visual analog measures. Similar results were not observed when the single-item approach was used in palliative care populations in the UK,⁵⁴ or Japan.⁵⁵ These contradictory findings, regarding the screening performance of a single-item screening approach, may be the result of differences in the way this item was applied or cultural differences, suggesting that further research investigating the utility of this measure is warranted.

In addition to single-item screening approaches, other measures are often used to screen for depression in patients with serious illnesses. Some of the more widely used tools include the Centre for Epidemiologic Studies Depression Scale (CES-D),⁵⁶ the Hospital Anxiety and Depression Scale (HADS),⁵⁷ and the Beck Depression Inventory-II (BDI-II).⁵⁸ The features of these measures are summarised in Table 2.

There has been increasing interest in demoralisation as an important clinical syndrome in the palliative care setting.⁵⁹ have identified a cluster of symptoms that distinguishes demoralization from depression, and, on the basis of their clinical studies, developed a Demoralization Scale, which provides a valuable tool for research on this increasingly recognised dimension of distress.⁶⁰

Table 1 Assessment methods for depression in patients with advanced illness

Diagnostic classification systems	Diagnostic and Statistical Manual DSM-IV
Structured Diagnostic Interviews	Endicott Substitution Criteria Research Diagnostic Criteria Schedule for Affective Disorders and Schizophrenia (SADS) Diagnostic Interview Schedule (DIS) Composite International Diagnostic Interview (CIDI) Structured Clinical Interview for DSM-IV (SCID)
Screening Instruments-Self Report	Beck Depression Inventory-13 items (BDI) General Health Questionnaire-30 (GHQ-30) Hospital Anxiety and Depression Scale (HADS) Visual Analog Scale for Depressed Mood

Adapted from Breitbart *et al.* (2004).

Table 2 Description of select screening instruments

Instrument	Origin and description	Current usage	Comments
Centre for Epidemiologic Studies Depressions Scale (CES-D)	Originally developed for use in non-psychiatric community samples 20-Item self-report measure of depressive symptoms 4/20 items are somatic	Widely used screening instrument Used in diverse medically ill populations	Evidence of sound psychometrics Positive predictive value low in some studies Lack of consensus regarding cutoff score
Hospital Anxiety and Depression Scale (HADS)	Designed for use in medically ill populations 14-item self-report scale with separate 7-item subscales for anxiety and depression	Extensive use in medically ill	Somatic items not included in depression subscale Brief High degree of patient acceptability Sensitivity to change Demonstrated concurrent and discriminant validity Lack of consensus regarding sensitivity and specificity as a screening tool and optimal cutoff scores to screen for minor depression and major depressive disorders
Beck Depression Inventory-II (BDI-II)	Designed as a measure of symptom severity in psychiatric patients 21-item self-report scale	Extensive use in medically ill	Number of somatic items may affect validity in palliative patients Forced-choice answer format and detailed response alternatives may confuse some patients

Adapted from Rodin *et al.* (2005).

Approaches to method and measurement follow conceptual decisions,⁶¹ therefore, the selection of a measure of depression for research purposes must not be arbitrary. Depression is complex and multidimensional. Moreover, those who design instruments hold a particular view about the nature of depression, which, in turn, influences the cognitive, somatic and behavioral domains that are indexed.⁶² The confounding effects of physical illness on symptoms, which are usually indicative of depression in other populations (eg, fatigue, poor concentration, sleep disturbance, appetite and weight change), need to be considered when using any screening or diagnostic tools for depression. Researchers cannot assume, then, that all depression scales measure the same construct. An item analysis of widely used depression scales, conducted by,⁶² revealed marked variability in the areas of psychopathology which each scale addressed, with some placing greater emphasis upon the assessment of anxiety than upon depressed mood. Therefore, researchers must be cognisant of the items that constitute the measure(s) they use when conducting investigations, and ensure that they are conceptually congruent with the definition of depression informing the study to be conducted (eg, either depressive symptoms, depression as a disorder, or measurement of general psychological distress or depressed mood).

Anxiety

Anxiety is a commonly encountered symptom in palliative care, reported by 30-60% of patients with advanced cancer and those in the terminal phase of illness.⁶³ Although there are limitations to the validity of currently available structured diagnostic instruments in this population, recent studies using the SCID indicate rates of specific anxiety disorders, such as panic disorder, at 4.8%,⁶⁴ a rate substantially higher than general population rates for recent (12 month) panic disorder (0.8–2.7%).^{44,45}

Anxiety, similar to depression, is a symptom that exists along a continuum, from distress that is common and might arise periodically (as discussed above), through to disabling anxiety indicative of a specific psychiatric syndrome. Furthermore, anxiety symptoms may mimic physical illness (eg, cardiovascular symptoms or breathlessness of a panic attack) or may contribute to an accentuation of existing physical symptoms, such as the exacerbation of dyspnoea in a patient with lung disease. Anxiety may occur as a symptom of physical illness or its treatments, or result from other primary causes (eg, substance withdrawal). Primary anxiety disorders are characterised by their impact on functioning, the persistence of the symptoms over time, as well as the presence of some core associated features (eg, in panic disorders,

the frequency of panic attacks). Anxiety and anxiety disorders frequently co-exist with depression.⁶⁴

Anxiety: diagnostic measures and screening tools. Anxiety symptoms and/or distress levels experienced by a patient are included in a number of general palliative care assessment measures, such as the Palliative Care Outcome Scale (POS),⁶⁵ the Edmonton Symptom Assessment Schedule (ESAS),²⁵ and the European Organization for Research on Cancer Treatment Quality of Life Questionnaire (EORTC).⁶⁶ These measures include an assessment of anxiety or 'emotional' functioning, based on patient self-report. They are set among items that address common physical symptoms, such as fatigue, pain and nausea (eg, POS, ESAS, EORTC), or can be supplemented by staff assessment (eg, POS). Some instruments also seek to evaluate the impact of any symptoms on functioning or level of concern attached to a symptom, eg, the Cambridge Palliative Assessment Schedule,⁶³ and the Memorial Symptom Assessment Scale.⁶⁷ While these instruments play an important role in clinical research in palliative care, they do not provide sufficient information to enable diagnosis of anxiety disorders.

The most widely used tool for anxiety in this setting is the HADS,⁵⁷ as described above. The HADS provides separate depression and anxiety subscales, and the anxiety subscale has been used to monitor the course of anxiety symptoms over time,⁶⁸ although the full scale may be the most effective in screening for psychological disorders.⁶⁹ While the HADS may be superior to other general psychological symptom measures (such as the General Health Questionnaire) in palliative care patients,^{70,71} concerns regarding its sensitivity and specificity as a screening tool in palliative care have been raised.⁶⁹

Other anxiety measures are available, but have not been developed specifically for use in physically ill populations. An example is the State-Trait Anxiety Inventory, a 40-item measure, is widely used in other clinical fields, but has had less application in palliative care settings than the HADS.⁷²

As with depressive disorders, the clinical interview is considered the 'gold standard' approach to detecting anxiety disorders. Structured diagnostic interviews have been developed to maximise the reliability of such assessment, although their use in the palliative care setting can be problematic, as previously discussed. Nevertheless, valuable data has been obtained from studies using structured clinical interviews in palliative care populations to determine the patterns of common psychiatric disorders, and associated factors, such as access to health services.^{73,64} The SISC,²⁶ described earlier, assesses anxiety symptoms, common physical symptoms and key end-of-life issues and concerns in

palliative care (eg, sense of burden, loss of dignity, desire for death).

Anxiety: other related models of distress. Other forms of anxiety include post-traumatic stress responses in reaction to life-threatening illness or its treatments.⁷⁴ This reaction is generally assessed through either brief self-report measures (such as the Impact of Events Scale, which identifies intrusive and avoidant symptom levels that are characteristic of post-trauma syndrome), or through detailed structured clinical interviews for reliable diagnosis of Post-Traumatic Stress Syndrome.^{73,75} Anxiety stemming from a threat to life, anticipation of death and existential concerns has been addressed by measures whose breadth include spiritual inquiry, as detailed earlier. Such measures provide an opportunity to understand the nature of the underlying anxiety and the derivation of this kind of distress. There is emerging research interest in existential distress among patients with advanced cancer or life-threatening illness¹⁸, as evidenced by the development of a measure to explore spiritual concerns, such as the System of Belief Inventory.⁷⁶

Delirium

Delirium is an acute organic brain syndrome that commonly occurs in the palliative care setting. The estimated prevalence rates are 20–40% on admission to palliative care services, with prevalence rates increasing substantially in terminally ill patients near death.^{77,78} The clinical manifestations of delirium are diverse, encompassing a broad range of behavioural, emotional and cognitive changes. As a result, it is frequently misdiagnosed and generally under-recognised.⁷⁹ The key sign of delirium is an altered state of consciousness. This may cause diverse clinical manifestations, which include disturbance in mood (eg, depression, anxiety, irritability), perception (eg, illusions, hallucinations) and behavioral changes (agitation, psychomotor slowing), alongside acute global cognitive impairment. Characteristically, delirium has an acute onset and fluctuating clinical signs. The diagnosis of delirium requires instruments and methods that address its core features: temporal instability, cognitive impairment, perceptual disturbance and secondary mood and/behavioral consequences. Specific delirium subtypes have been documented (mixed, hypoactive or hyperactive), based on the level of behavioral agitation or withdrawal.⁷⁸ The DSM-IV criteria for delirium include cognitive impairment, disturbance of consciousness and perception, behavioral change and organic etiology, detected through physical examination and investigations.⁸⁰ The condition causes significant distress and disability for the patient and the patient's family and carers, affecting communication and frequently interfering with the identification and manage-

ment of other symptoms (eg, pain, depression).⁷⁸ A specific obstacle to research and clinical practice regarding delirium is the lack of consistency in terminology used to describe it, and the tendency for clinicians to describe any cognitive impairment in the palliative care setting⁸¹ as delirium. Such nomenclature does not differentiate important distinct diagnostic groups (eg, delirium, dementia, or focal brain syndromes), whose common feature includes the undermining of cognitive acuity. Due to its acute onset and fluctuating course, the diagnostic assessment of delirium needs to include observations over time, and evaluation of the full range of cognitive, mood and behavioral changes. Since delirium is a condition that has substantial impact on judgment and cognition, assessment tools rely heavily on observer ratings rather than self-rating instruments, which are commonly applied across various other psychiatric syndromes.

Delirium: diagnostic measures and screening tools. As with anxiety and depression, some instruments that assess general functioning in palliative care also include assessment of subjective complaints of cognitive impairment. The diagnosis of the underlying cause of any specific cognitive complaint requires detailed specific assessment, using tools as outlined below. Measures, such as the self-report EORTC, identify self-perceived difficulties with cognitive function as part of an overall evaluation of quality of life and key problems. Such global assessment is not sufficient when screening for cognitive impairment.⁸¹ Furthermore, the validity of self-reported complaints of cognitive impairment needs to be considered with caution when assessing cognitive function.^{81,82} These tools need to be used in combination with more specific ratings or assessments of clinical signs and symptoms in studies of delirium.

The Mini Mental State Examination (MMSE)⁸³ is the most widely used clinician-rated instrument to screen for cognitive impairment, and is commonly used in palliative care research.⁸¹ Total scores <24 generally indicate cognitive impairment requiring further assessment. The MMSE does not differentiate among the potential causes of cognitive impairment (eg, delirium or dementia),^{79,78} and is useful only as a screen to be followed by more detailed assessment. A short version of the MMSE has been developed, which increases its utility in palliative care while maintaining sensitivity and specificity.⁸⁵ It is important to recognise the affect of education, age and cultural factors on MMSE performance, along with hearing deficits, visual impairment or challenges in language-related functions.⁷⁹

A number of other measures have been used for cognitive screening in palliative care, including the brief Short Orientation Memory Concentration Test of Cog-

nitive Impairment (OMCT), the Bedside Confusion Scale (BCS)⁷⁹ and the Confusion Rating Scale (CRS).⁸¹

Tools for the diagnosis of delirium. The following measures provide information on cognitive performance, but additionally, for diagnostic purposes, address the key symptoms of delirium.

The Memorial Delirium Assessment Scale (MDAS)⁸⁶ has been specifically developed among patients with cancer and AIDS, and is, thus, particularly appropriate in the palliative care setting. The MDAS includes items that are representative of the many features of delirium, reflecting DSM-IV criteria and enabling detection of both hypoactive and hyperactive forms of delirium.⁸⁷ The MDAS is useful for monitoring the severity of delirium; threshold scores have been established for a diagnosis of probable delirium, while also allowing prorating of items, thus addressing the problem of patients being unable to participate or respond on some items.⁷⁸

The Confusion Assessment Method (CAM)⁸⁹ is a brief 9-item instrument, which has been used previously in palliative care research^{77,90}. Intended for application by trained clinicians, the CAM is comprised of a diagnostic algorithm, which requires the presence of an acute onset and fluctuating course, inattention, together with disorganised thinking or altered level of consciousness.⁹⁰ It can also be used for regular monitoring of delirium.

The Delirium Rating Scale (DRS) is also useful for monitoring delirium severity, and similar to the MDAS, can act as a diagnostic instrument. The DRS contains only one item on cognitive status, but includes the breadth of key phenomenology associated with the delirium syndrome (eg, sleep wake cycle disturbance, temporal onset, mood lability, variability of symptoms). An adaptation for children has been undertaken,⁹² thereby enhancing this instrument's utility for research across the lifespan.

The Communication Capacity Scale and Agitation Scale (CCSAS),⁹² has been developed to address problems that delirious palliative patients experience in completing key assessment items. The CCSAS relies on observations of behavior and communication (eg, language, etc.), which may interfere with the patient's ability to undertake assessment of memory or higher cognitive functions (eg, repeat items, or perform calculations).

In the clinical setting, the diagnosis of delirium and its causes also relies on appropriate physical examination and laboratory investigation. Physical examination and clinical investigations form part of the clinical management of patients with delirium, and focus on trying to identify causative and contributory factors underlying this disorder. For research purposes, a range of biological measures has been used to investigate the pathophysiology of delirium, including functional neuroimaging,

serum anticholinergic activity and EEG Erhardt⁷⁹. Neuroimaging tools are less practical for research purposes in the palliative care setting. Detailed neuropsychological testing is not addressed in this review. Detailed neuropsychological assessment is usually neither clinically applicable nor necessary for the clinical diagnosis of delirium. Tests of specific psychomotor functions (eg, visuospatial ability) may be highly reliable in screening for cognitive impairment, but will not provide the breadth of information needed for a diagnosis of delirium.⁷⁹

*Other delirium-related measures.*⁹³ developed the Delirium Experience Questionnaire, to address the effect of delirium on patients, carers and family members. This approach has been valuable (and largely unaddressed within the palliative care literature) by way of tapping into the subjective experience of delirium according to the recollections of patients, their carers and families.

For a comprehensive review of research methods and a full range of tools available to address delirium in palliative care, see,⁸¹ and a review of delirium measurement by.⁷⁹

Conclusion

Research methods addressing psychological distress in palliative care patients have contributed to our understanding of the needs and experiences of individuals approaching death. These methods include established psychiatric and psychological research tools, which provide valuable comparability with other clinical populations. Screening tools are used to identify key distress related symptoms and may indicate the presence of common clinical syndromes. In the presence of significant distress, screening approaches need to be supplemented by more detailed, diagnostic assessment instruments. There is also a need to consider the broader psychological dimensions of suffering in this group, including, for example, attention to existential concerns, spirituality, hope and demoralisation.

Instrument development, tailored to the particularities of vulnerable populations, has helped reduce participant burden, while maintaining validity and reliability for research and clinical purposes. This includes brief single-item screening tools, and measures that are specific to palliative care populations, which identify domains of particular significance (eg, desire for death, demoralisation, sense of burden, spiritual concerns). In order to ensure research is as informative as possible, it has been necessary to both adapt existing psychological frameworks, as well as moving beyond existing nosological categories, thereby encompassing these broader psychological domains. Palliative care research must always

remain cognisant of the complex interaction between psychological, physical and social dimensions of distress, and the various practical issues that may influence the reliability and validity of applied instruments in this setting.

While this review has focused on quantitative methods for screening and detection of psychological distress, it is important to recognise the contribution of qualitative methods in psychological research of this nature. The latter provides a well established approach to exploring the experiences and concerns of patients receiving palliative care, adding further depth to our understanding of psychological distress and suffering in this population. In assembling a palliative care research protocol, the selection of psychometric instruments, and the choice of research methods applied, must balance the need to retrieve reliable data that will answer the posed research question, while at the same time, minimise patient burden and maintain the highest standards of ethical research conduct. Vigilance in maintaining this balance lies at the foundation of conducting a successful program of research amongst patients whose lives are quickly drawing to a close.

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